Schizophrenia:

Youth's Greatest Disabler

Face it

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Note Change

In 1990 both the Canadian Friends of Schizophrenics and the Alberta Friends of Schizophrenics opted to change their respective organizational names to the Schizophrenia Society of Canada and the Schizophrenia Society of Alberta. Other provincial chapters may choose to change their names in the future.

A Letter to Young People, Educators, Parents and Others

Dear Reader:

If you would like to know some of the basic facts about schizophrenia, you will find this publication particularly useful. The booklet is meant to be an introduction to the topic and, therefore, should not be used as a diagnostic tool.

The information contained herein is taken with permission from books, articles and personal experience. Although carefully researched, this booklet may contain some errors and omissions. Therefore, if you require more information about schizophrenia, we urge you to seek the advice of a mental health professional.

Please note that the content of this booklet has been arranged in such a manner that each section can be used as a separate handout. Users are welcome to reproduce these sections in quantity provided they are required for bona fide educational purposes.

We would very much appreciate hearing from you with comments on the usefulness of this publication and/or ideas for future improvement. You can contact us at:

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The Facts About Schizophrenia: No One Is Immune

"Not only victims but also families and friends are affected by schizophrenia, each in different ways. Their sufferings are immeasurable, as are the social and financial costs to communities at large."

Seeman, Littman, et al

The Facts:

Schizophrenia is a common illness

- It is found all over the world in all races, in all cultures, and in all social classes.
- In Canada, it affects 1% of the population or 1 in every 100 people.

Men and women are affected with equal frequency

- In the 16 to 20 year-old age group, more men than women are affected by schizophrenia.
- In the 25 to 30 year-old age group, the opposite is true. More women than men are affected by schizophrenia at this age.

Schizophrenia is one of youth's greatest disablers

- Most frequently, the illness occurs in the 16 to 30 year-old age group.
- It can also appear later in adulthood. However, onset (occurrence) after age 35 is less common and onset after age 40 is rare.
- Although very rare, a childhood form of the illness exists. It can be found in children over the age of five years.

We are all affected

- More hospital beds are occupied by persons with schizophrenia than by sufferers of any other medical condition.
- The costs to society due to hospitalization, disability payments, welfare payments and lost wages rank in the billions of dollars annually.
- Other costs associated with the loss of individual potential, personal anguish and family hardship are impossible to measure.

What Is Schizophrenia?

"SCHIZ-O-PHRE-NI-A, n. Any of a group of psychotic reactions characterized by withdrawal from reality with highly variable affective, behavioral and intellectual disturbances."

American Heritage Dictionary

"Schizophrenia is a syndrome (group of symptoms) characterized by delusions, by hallucinations, by disturbances in thinking and communication, and by deteriorating social functioning."

Edward Sachar, M.D.

"The talent submerged, the promise broken, the future lost, the life taken. This is schizophrenia. Aimless, hopeless, wandering, waiting ... waiting for the brain to reconnect."

Trish Van Devere, actress

No definition of schizophrenia can adequately describe all people with this illness. Schizophrenia is an extremely complex mental illness.

It is clear that schizophrenia is a disease which makes it difficult for the person with the illness to decide what is real and what is not real.

It is also clear that this brain disease affects normal, intelligent people in all walks of life.

Given proper support, many of those with the illness can learn how to deal with it and lead reasonably comfortable lives.

Schizophrenia:

. . . is a real disease (or group of diseases)
. . . has concrete and specific symptoms
. . . is different from other mental illnesses
. . . is the result of flawed brain biochemistry
. . . may be treated by specific antipsychotic drugs
. . . often has a genetic component
. . . is almost always treatable
. . . in some cases, remits

What Causes Schizophrenia?

"We do not yet understand precisely the cause or causes of schizophrenia, although research is progressing rapidly."
Seeman, Littmann, et al

Scientists are almost certain that schizophrenia has more than one cause. Some possible causes are discussed below:

- **Chemical imbalance**
  An imbalance of the brain's chemical system has long been suspected as the main cause of the illness. Some researchers suspect neurotransmitters (the substances which allow communication between nerve cells) while others point to an excess or lack of dopamine (chemical substance in the brain). The limbic system (the area of the brain involved with emotion and perception that acts as a gate for incoming stimuli or messages) is thought to be the area affected in most types of schizophrenia.

- **Stress**
  The role of stress in schizophrenia is unclear. Most authorities disagree whether severe stress causes the illness. However, they acknowledge that stress can trigger or worsen the symptoms when the illness is already present.

- **Infections**
  While infections can cause brain inflammation (swelling) and create changes in the limbic system, they have not been definitely linked to schizophrenia.

- **Viruses or virus-like particles**
  Some feel that "slow viruses" may be to blame since signs and symptoms are delayed and may occur many years after the first infection.

- **Genetic predisposition**
  Schizophrenia occurs in 1% of the general population but children with one schizophrenic parent have a 10% chance of developing the illness. When both parents have schizophrenia, the percentage of risk rises to approximately 40%. The work of Canadian scientists Dr. B. Jones and Dr. A. Bassett pointed the way for the British research team under Dr. Gurling which discovered a clear genetic linkage in some forms of schizophrenia. More research studies are required to follow-up this promising advance.

- **Drug abuse**
  Drugs (including medications, alcohol, tobacco and street drugs) themselves do not cause schizophrenia. However, certain drugs such as amphetamines can make psychotic symptoms worse if a person already has schizophrenia. As well, these same drugs can create schizophrenia-like symptoms in normal persons when the dosage is large.

- **Nutritional theories**
  While scientists recognize that proper nutrition is essential for the well-being of a person with the illness, they do not agree that a lack of certain vitamins causes schizophrenia. "Cures" with megavitamin therapy are unproven and often very expensive.

  Some people do improve while taking vitamins; however, this may be due to the antipsychotic medication they are taking at the same time, the therapeutic effect of a structured diet, vitamin and medication regime, or they may be part of the 30% who recover no matter what treatment is used.

While the causes are unclear, schizophrenia definitely is:

. . . NOT caused by childhood experiences
. . . NOT caused by poverty
. . . NOT caused by domineering mothers and/or passive fathers
. . . NOT caused by poor parenting
. . . NOT caused by guilt, failure or misbehavior

Schizophrenia:

. . . is a real disease (or group of diseases)
. . . has concrete and specific symptoms
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. . . is the result of flawed brain biochemistry
. . . may be treated by specific antipsychotic drugs
. . . often has a genetic component
. . . is almost always treatable
. . . in some cases, remits

What Are the Symptoms of Schizophrenia?

"I just couldn't accept the fact that he had an above average I.Q., was good-looking, had a good personality, and was ill."
Parent of a child with schizophrenia

Just as other illnesses have signs or symptoms, so does schizophrenia. However, the symptoms are not identical for each person who has the illness. Approximately one-third of those affected may have only one episode of schizophrenia in his/her lifetime while another one-third may have recurring or continual episodes but lead relatively normal lives in between. A final one-third have symptoms for a lifetime.

Schizophrenia always involves deterioration and changes from a previous level of functioning. Family members and friends often notice that the person is "not the same". The person with schizophrenia has difficulty in separating what is real from what is unreal. As the person becomes more stressed by the demands of day to day living, the person may withdraw and the symptoms become more pronounced. Deterioration is noticeable in areas such as:

- work or academic achievement
- how one relates to others
- personal care and hygiene

The Characteristic Signs and Symptoms of Schizophrenia

The symptoms of schizophrenia may be noticed in several of the following areas:

- **Personality changes** are a key to recognizing schizophrenia. At first, the changes may be subtle, minor and go unnoticed. As they worsen they become obvious to family members, friends and co-workers. There is a loss of feeling or emotions, a lack of interest and motivation. A normally outgoing person becomes withdrawn, quiet, moody or inappropriate. The person may laugh when told a sad story, may cry over a joke, or may be unable to show any emotion at all.

- **Thought changes**, one of the most profound changes, is the barrier to clear thinking and normal reasonableness. Thoughts may be slow in forming, or come extra fast or not at all. The person may jump from topic to topic, seem confused or have difficulty reaching easy conclusions. Thinking may be coloured by **delusions** and false beliefs that resist logical explanations. A person may express strong ideas of persecution, convinced that he/she is being spied on or plotted against. Others may experience grandiose delusions and feel like Superman, capable of anything and invulnerable to danger. Some may feel a strong religious drive or mission to right the wrongs of the world.

- **Perceptual changes** turn the world of the ill person topsy-turvey. The nerves carrying sensory messages to the brain from the eyes, ears, nose, skin and taste buds become confused and the person sees, hears, smells and feels sensations which are not real. These are called **hallucinations.**

Frequently, persons with schizophrenia hear voices in their heads condemning them or giving orders such as "hang yourself". **There is always the danger that the order will be obeyed.** These people see things that others do not see: a door in a wall where no door exists; an imaginary tiger; or a long-dead relative suddenly entering the room; carpets may appear to be walking; colors, shapes and faces may appear to change before the person's eyes. There may be hypersensitivity to sounds, tastes and smells. The ring of a telephone may seem to be as loud as a fire alarm bell or a loved one's voice as threatening as a lion's roar. The sense of touch may be distorted. They may feel that things are crawling across their skin, or on other occasions they may feel nothing, not even real pain.

- **Sense of self.** When one or all five senses are affected, the person may feel out of time, out of space, free floating and bodiless and non-existent as a person.

It is not difficult to understand why the individual who experiences these profound and frightening changes will seek to keep them secret, deny that anything is happening or avoid people and situations where they may be discovered.

These intense internal experiences will trigger other feelings of panic, fear and anxiety — natural reactions to what they are going through — feelings which can further amplify their extreme emotional states. The psychological pain will be intense, most of it kept inside, its existence denied.

The pain of schizophrenia is further accentuated by the person's awareness of the anguish and suffering they are causing their family and friends. This is why those who suffer from schizophrenia require so much understanding, patience and reassurance that they will not be abandoned.

The Signs of Relapse

Families and friends of those with schizophrenia should be aware of the signs that the illness is getting out of control again. It is useful to know that relapse usually begins in the same manner for each individual. The signs vary from person to person but those most commonly reported are:

- sleeplessness for several nights in a row
- the mind begins to "play tricks" on the person
- increased withdrawal from activities
- deterioration of basic personal care

You should be aware that:

- stress and tension make symptoms worse
- symptoms improve as the person gets older

Early Warning Signs Noticed by Families

The following is a list of early warning signals of mental illness. It was developed by families who had a member affected with schizophrenia. It should be noted that many of the behaviors listed are within the normal range. These families concluded, however, that even with the mildest of symptoms, there was a vague yet distinct awareness that the person's behavior was "unusual", had "changed" or was "not the same".

Social withdrawal was observed by everyone. Most families commented that the child has been a "good child, never causing any trouble" but was "seldom outgoing" during the growing years. Prior to development of the illness, families observed one or more than one of the following symptoms. The number and severity of these symptoms vary from person to person. The important factor is the **contrast** from previous behavior.

One of the difficulties in reading the "early warning signs" of schizophrenia is the easy confusion with some typical adolescent behavior. Schizophrenia can begin to affect an individual during the teen years, a time when many rapid physical, social, emotional and behavioral changes normally occur. There is no easy method to tell the difference. It's a matter of degree. This is where the advice of a trained mental health specialist is essential.

Most Common Signs

- Social withdrawal, isolation and reclusiveness
- Deterioration and abandonment of personal hygiene
- Flat emotions
- Inability to express joy
- Inability to cry or excessive crying
- Inappropriate laughter
- Excessive fatigue and sleepiness or an inability to sleep

Other Signs

- Sudden shift in basic personality
- Depression, intense and unremitting
- Deterioration of social relationships
- Inability to concentrate or cope with minor problems
- Indifference, even in highly important situations
- Dropping out of activities (and life in general)
- Decline in academic or athletic performance
- Unexpected hostility
- Hyperactivity or inactivity or alternating between the two
- Extreme religiousness or preoccupation with the occult
- Drug or alcohol abuse
- Forgetfulness and loss of valuable possessions
- Involvement in auto accidents
- Unusual sensitivity to stimuli (noise, light, clothing)

- Extreme devastation from peer or family disapproval
- Noticeable and rapid weight loss
- Attempts at escape through geographic change; frequent moves or hitch-hiking trips
- Excessive writing (or childlike printing) without apparent meaning
- Early signs of migraine
- Fainting
- Bizarre behavior (skipping, wearing torn clothing exclusively, etc.)
- Irrational statements
- Strange posturing
- Refusal to touch persons or objects; insulation of hands with paper, gloves, etc.
- Shaving head or removal of body hair
- Cutting oneself; threats of self mutilation
- Staring, not blinking or blinking incessantly
- Flat, reptile-like gaze
- Rigid stubborness
- Peculiar use of words or language structure
- Sensitivity and irritability when touched by others

Recent studies indicate that families who are supportive, non-judgemental and, most especially, non-critical tend to aid or facilitate the recovery process. These studies also show that patients who spend a great deal of time at home with chaotic or volatile family members tend to return to psychiatric hospitals more often than the former group. Thus, it is important for all families to assess their coping skills and learn to anticipate the ups and downs of the illness. Your assistance and support can make a difference to the person with schizophrenia.

Types of Schizophrenia

To make the diagnosis and treatment of schizophrenia easier and more effective, psychiatrists have attempted to classify schizophrenia into several types. These classifications are based on years of experience and research with symptoms and feelings described by patients and observations made by family members, nurses, doctors and psychiatrists. Since single symptoms of schizophrenia may be caused by other diseases or illnesses, it is most important to seek help early from physicians and psychiatrists.

Before identifying the specific type of schizophrenia, the doctor or psychiatrist should look at the family history and personal history of the person affected, dc a thorough physical examination and order laboratory and x-ray examinations. Once all of the information is analysed, and if the person has schizophrenia, a diagnosis may be made using one of the following categories of schizophrenia.

- **Disorganized Type**
  This type of schizophrenia, commonly referred to as the "hebephrenic" type, has the following diagnostic criteria:
  - Early symptoms include poor concentration, moodiness, confusion and strange ideas.
  - The person's speech is frequently incoherent, difficult to understand, rambling.
  - Delusions or false beliefs are not well established.
  - The person shows no emotions or they are inappropriate, i.e. silly, giddy laughter.

- **Paranoid Type**
  Characterized by delusions and/or hallucinations with persecution, or less commonly an exaggerated sense of self importance. Other features exhibited for no apparent reason may be: anxiety, anger, argumentativeness, jealousy and occasionally violence.

- **Catatonic Type**
  Diagnostic criteria for the catatonic type of schizophrenia include:
  - Catatonic stupor (marked decrease in reaction to one's environment) or mutism (no speech).
  - Motionless resistance to all instructions or attempts to be physically moved.
  - Maintenance of a rigid or bizarre posture.
  - Excited physical activity which seems purposeless, not influenced by the person's environment.

- **Undifferentiated Type**
  Sometimes the major psychotic symptoms cannot be classified into any category listed, or may match the criteria for more than one type of schizophrenia.

- **Residual Type**
  This category is used when there is at least one recognizable episode of schizophrenia but no ongoing obvious psychotic symptoms, though less clear signs of the illness continue such as social withdrawal, eccentric behavior, inappropriate emotions, illogical thinking, etc.

What It Is Like to Have Schizophrenia

In the following excerpts from her life story, Esso Leete describes her 20-year battle with schizophrenia and her growing acceptance of her illness. She has committed herself to leading the fullest life her disease will allow and to educating others about mental illness. She is employed full-time as a medical records transcriptionist at a hospital where she was once committed.

"It has been 20 years since I first became mentally ill. As I approach 40, I find myself still struggling with the same symptoms, still crippled by the same fears and paranoia. I am haunted by an evasive picture of what my life could have been, whom I might have become, what I might have accomplished. My schizophrenia is a sad realization, a painful reality, that I live with every day.

Let me tell you a little about my history. I probably inherited a predisposition to mental illness; my uncle was diagnosed as having "dementia praecox," an earlier term for schizophrenia. In my senior year of high school, I began to experience personality changes. I did not realize the significance of the changes at the time, and I think others denied them, but looking back I can see that they were the earliest signs of illness. I became increasingly withdrawn and sullen. I felt alienated and lonely and hated everyone. I felt as if there were a huge gap between me and the rest of the world; everybody seemed so distant from me.

I reluctantly went off to college, feeling alone and totally unprepared for life away from home. I was isolated and had no close friends. As time went on, I spoke to virtually no one. Increasingly during classes I found myself drawing pictures of Van Gogh and writing poetry. I forgot to eat and began sleeping in my clothes. Performing even the most routine activities, such as taking a shower, rarely even occurred to me.

Toward the end of my first semester, I had my first psychotic episode. I did not understand what was happening and was extremely frightened. The experience left me exhausted and confused, and I began hearing voices for the first time.

I was admitted to a psychiatric hospital, diagnosed as having schizophrenia, treated with medications and released after a few months.

During my late teens and early 20s, when my age demanded that I date and develop social skills, my illness required that I spend my adolescence on psychiatric wards. To this day I mourn the loss of those years.

It was not until much later that I made a conscious effort to develop a sense of control, realizing that I had the power to decide what form my life would take and who I would be.

For the next ten years, I did not require hospitalization. During that time, I was divorced from my first husband and married a community mental health center psychiatrist. Although I experienced some acute flare-ups of symptomatology during that period, I had no recurrence of persistent, disabling symptoms.

When more serious symptoms returned about ten years later, I denied their existence. Having discontinued medications years earlier and now withdrawing from other forms of support, I experienced more symptoms.

I decided to investigate a private psychiatric residential halfway house that one of the nurses at the hospital had told me about. I sought and gained admission to the program. Staff at this facility believed in my potential, and I began to develop confidence in myself.

I was now ready to take control of my life. My estranged second husband and I moved into an apartment together, and I threw myself into the task of finding employment. None of these steps were accomplished easily, but the pieces of my periodically disrupted life were coming back together.

Like those with other chronic illnesses, I know to expect good and bad times and to make the most of the good. I take my life very seriously and do as much as I can when I am feeling well, because I know that there will be bad times when I am likely to lose some of the ground I have gained. Professionals and family members must help the ill person set realistic goals. I would entreat them not to be devastated by our illnesses and transmit this hopeless attitude to us. I would urge them never to lose hope, for we will not strive if we believe the effort is futile."

From the article, "The Treatment of Schizophrenia: A Patient's Perspective", *Hospital and Community Psychiatry,* Vol. 38, No. 5, May, 1987.

How Schizophrenia Affects Family Members

"The typical family of a mentally ill person is often in chaos. The parents look frantically for answers that usually can't be found. Hope turns to despair, and some families are destroyed no matter how hard they try to survive."

Parent of a schizophrenic child

When a family learns that their child has schizophrenia, their emotions are similar to those experienced when a major illness or accident occurs. In other words, they feel shocked, sad, angry and dismayed. Some of these families have shared their feelings:

- **Sorrow** ("We feel like we lost a child.")
- **Anxiety** ("We're afraid to leave him alone or hurt his feelings.")
- **Fear** ("Will we be safe from physical harm? Will the ill person harm himself or herself?")
- **Shame and guilt** ("Are we to blame? What will people think?")
- **Feelings of isolation** ("No one can understand.")
- **Bitterness** ("Why did this happen to us?")
- **Ambivalence toward the afflicted person** ("We love him a great deal but when his disability causes him to be cruel, we also wish he'd go away.")
- **Anger and jealousy** ("Siblings resent the attention given to the ill family member.")
- **Depression** ("We can't talk without crying.")
- **Complete denial of the illness** ("This can't happen in our family.")
- **Denial of the severity of the illness** ("This is only a phase that will pass.")
- **Blaming each other** ("If you had been a better parent . . .")
- **Inability to think or talk about anything but the illness** ("All our lives were bent around the problem.")
- **Martial discord** ("My relationship with my husband became cold. I seemed dead inside.")
- **Divorce** ("It tears a family apart.")
- **Preoccupation with "moving away"** ("Maybe if we lived somewhere else, things would be better.")
- **Sleeplessness** ("I aged double time in the last seven years.")
- **Weight loss** ("We have been through the mill, and it shows in our health.")
- **Withdrawal from social activities** ("We don't attend family get-togethers.")
- **Excessive searching of the past for possible explanations** ("Was it something we did to him?")
- **Increased drinking/use of tranquilizers** ("Our evening drink turned into three or four.")
- **Concern for the future** ("What's going to happen after we're gone? Who will take care of him/her?")

The "Blame and Shame" Syndrome

"People do not cause schizophrenia, they merely blame each other for doing so."

E. Fuller Torrey, M.D.

Unfortunately, a common tendency is for family members and the afflicted person to blame one another. Moreover, sisters and brothers often share the same shame and fear that their parents do.

In the following story, a parent describes "blame and shame" from personal experience:

> "I have two sons. My older son is 22 and is in an advanced stage of muscular dystrophy. My younger son is 21 and has been diagnosed as chronically mentally ill.
>
> The son that is disabled physically has many special needs. He gets emotional support everywhere he turns. His handicap is visible and obvious and the community, family and friends open their hearts to him and go out of their way to make his life better.
>
> My other son, on the other hand, is misunderstood and shunned by all. He is also terribly disabled but his disability is not visible.
>
> His grandparents, aunts, uncles and cousins all think that he's lazy, stupid, weird and "naughty". They suggest that somehow, we have made some terrible mistake in his upbringing. When they call on the phone they ask how his brother is and talk to his brother but they never inquire as to him. He upsets them. They also wish that he'd go away."
>
> Excerpted from *Alliance for the Mentally Ill of Southern Arizona Newsletter*

With time, a good understanding of the illness, and support from others who are experiencing the same challenges, family members can learn to share their feelings and reduce the blaming and the shame. In the process, many families discover great strength and deep reserves of love for one another.

The Role of Families in Dealing with Schizophrenia

"Research on families of schizophrenics has found that good family environments can be a major factor in improving the chances of stabilizing the disease and preventing serious relapses."

Dr. Ian Falloon, et al

"Compassion follows understanding. It is therefore incumbent on us to understand as best we can — the burden of disease will then become lighter for all."

E. Fuller Torrey, M.D.

The family can play a very important role in all aspects of assisting the person with schizophrenia. If schizophrenia is a concern in your family, you may wish to note the following:

Warning Signs

When peculiar behavior is experienced, or observed, it makes good sense to seek advice from a psychiatrist. Keep in mind that a schizophrenic episode may erupt suddenly or symptoms may develop over a period of time. The following signal a need for attention:

- marked changes in personality
- a constant feeling of being watched
- difficulty in controlling one's thoughts
- hearing voices or nonexistent sounds
- increasing withdrawal from social contacts
- seeing persons or things that aren't there
- use of words that make no sense
- sudden excesses such as extreme religiosity
- irrational, angry, or fearful responses to loved ones
- sleeplessness and agitation

Caution is in order because such seemingly telltale symptoms, even in combination, may not be evidence of schizophrenia. They might be evidence only of an overworked imagination or extreme stress due for example to loss of status or a death in the family. The crucial factor is the relative ability to turn off the imagination. Today, increasingly precise diagnosis helps to ensure that warning signs are not misinterpreted.

The man or woman, young or old, once diagnosed as a borderline schizophrenic might now be described as having a borderline personality disorder – eccentric, unpredictable, and sometimes irrational. Such a person may be able to function in everyday life, though not at full capacity.

Getting Treatment

- **Take the initiative. Ask your family doctor for an assessment when the symptoms of mental illness are suspected.**
  Family members will likely be the first to recognize that it is necessary for the affected person to consult a physician for advice. Remember that the ill person believes that the hallucinations, delusion or other symptoms are real, and so may resist treatment.

- **Be persistent. Find a doctor/psychiatrist familiar with schizophrenia.**
  The assessment and treatment of schizophrenia should involve medical people who are well-qualified. Choose a specialist who has an interest in the illness, who is competent and has empathy with patients. Always remember that if you lack confidence in a physican/psychiatrist, you have the right to seek a second opinion from another doctor, even if it means travelling to another town or city.

- **Assist the doctor/psychiatrist.**
  Since patients with the illness may not volunteer much information during an assessment, speak to the doctor yourself or write a letter. In some cases, it may be necessary to send written information. Be persistent. The information you supply will greatly assist the physican to make an accurate assessment and outline a suitable course of action.

- **Other sources of assessment and treatment.**
  Alberta Health is the provincial government department responsible for mental health services for Albertans. Assessment and treatment are available at government regional Mental Health Clinics throughout the province. For locations and phone numbers see the later section entitled **Community Services in Alberta For People With Schizophrenia.**

  Assessment and treatment may also be available from your physician, from community and private counselling services, and through local hospitals.

- **Tips for making first contact.**
  - Rehearse before you call. State what you need clearly and briefly. Get the name of the person you are talking with.
  - If you cannot get the help or information you need, ask to speak to a supervisor or person in charge.
  - If you cannot immediately reach your party, ask when you may expect a return call or when the person will be free for you to call back.

Helping to Make the Most of Treatment

- Unless the patient wishes to keep information about the illness confidential, family members should **press the doctor for information related to care and treatment.**
  Then you can discuss together:
  - signs and symptoms of the illness
  - the course of the illness
  - treatment strategies
  - the signs of relapse
  - other related information

- **Provide plenty of support and loving care for your loved one.**
  Help him or her to accept the diagnosis. Show by your attitudes and behavior that there is hope, the disease can be managed and life can be satisfying and productive.

- **Help the person with the illness to maintain a record of information on:**
  - what symptoms have appeared
  - what medications were taken and in what dosages
  - the effects of various types of treatment

- **Ensure that the person continues to receive treatment after hospitalization.**
  This includes:
  - taking medication
  - going for follow-up treatment

Managing From Day To Day

- **Provide a structured and predictable environment.**
  The recovering patient will have problems with sensory overload. In order to reduce stress, plan activities for each day and keep "big events" to a minimum. Keep routines simple and allow your loved one time alone each day.

- **Be consistent.**
  Caregivers should agree on a plan of action and follow it. If you are predictable in the way you handle recurring concerns, you will help to reduce confusion and stress for your loved one.

- **Maintain peace and calm at home.**
  You will want to keep voices down and speak at a slower pace. Shorter sentences will also help to reduce stress. Avoid arguing about delusions (false beliefs).

- **Be positive and supportive.**
  Being positive will probably be more helpful and effective in the long run than criticism. Like anyone else, mentally ill people need to know when they are doing well. Their self esteem is fragile and needs to be boosted regularly. Encourage all positive efforts.

  Express appreciation for a job even half done because schizophrenia creates a lack of:
  - confidence
  - initiative
  - patience
  - memory

- **Assist the ill person to set realistic goals.**
  Encourage your loved one to gradually regain former skills and interests. Try new things as well but work up to them gradually. If goals are unattainable or if you nag, stress can worsen the symptoms.

- **Gradually increase independence** when your loved one shows the ability to handle greater responsibility and is able to complete various types of chores. Set limits on how much abnormal behavior is acceptable and firmly and consistently apply the consequences. As well, some relearning may have to occur about the handling of money, cooking and housecleaning. If outside employment is too difficult, help the person learn how to use time constructively.

- **Together learn how to cope with stress.**
  Anticipate ups and downs and prepare accordingly. The mentally ill person needs to learn to deal with stress in a socially acceptable manner. Your positive role-modelling will be most helpful.

- **Encourage your loved one to get out into the community.**
  Allow your loved one to help select an appropriate activity when trying something new. If requested, go along the first time for moral support.

Looking After Yourself and Other Family Members

- **Be good to yourself.**
  Your good health is very important, even crucial to the best functioning of your entire family.

  Let go of guilt and shame. Take comfort and gain strength from the positive things your family has experienced together. No scientific evidence exists to show that poor childrearing or poor communication causes schizophrenia.

- **Value your own privacy.**
  Keep up friendships and outside interests and lead as orderly a life as possible.

- **Do not neglect other children.**
  Brothers and sisters often secretly share the guilt and fear of their parents. They may worry that they too may become ill. When their concerns are neglected because of the ill child, they can become jealous or resentful. These children need your love and attention, too.

- **Learn from and enjoy the support of others who have similar problems.**
  Check to see what resources are available in your community. You can share and learn from the experiences of others, you can benefit from educational programs and discussions, and you can work co-operatively with others to improve and increase services.

- **Call the Mental Health Clinic in your region** and ask if there is a family or parent education program which you can join.

- **Join the Schizophrenia Society of Alberta or similar family support organizations in your region.**
  These community resources offer support to families and self-help opportunities.

What Is Involved in the Treatment of Schizophrenia?

"Schizophrenia is not the dreaded disease it was about 30 years ago. Now, with early diagnosis, speedy initiation of treatment, careful monitoring of medication, regular follow-up, proper residential, vocational and rehabilitative support systems in place, the long-term outcome is quite favorable."

A psychiatric professional

"Health professionals talk about how things could be or should be. The way things are is that many crucial support systems do not exist. As a result, schizophrenia becomes a living hell for the sufferer and his family."

Parent of a young man with schizophrenia

How Does a Family Obtain Appropriate Medical Help?

Schizophrenia may resemble other disease processes. The assessment and treatment of schizophrenia should involve well-qualified people.

Seek the advice of your family doctor or psychiatrist before accepting any unusual treatment or making any changes in your current treatment program. If you are uneasy or lack confidence in the advice you receive, remember that you have the right to seek another opinion from another doctor/psychiatrist, even if from another city. When seeking a specialist, you will want someone who is medically competent, who has an interest in the disease and who has empathy with its sufferers. More specifically, you will want assistance from a psychiatrist who:

- believes schizophrenia is biologically based;
- takes a detailed history;
- screens for many clearly noticeable problems that appear to indicate schizophrenia but are related to another illness;
- uses antipsychotic drugs wisely and carefully;
- follows up thoroughly;
- when necessary, corrects the course of treatment;
- reviews medications regularly;
- is interested in the patient's entire welfare and makes appropriate referrals for aftercare, housing, social support and financial aid;
- involves the parents in the process of treatment;
- explains fully what is going on.

Persons who tell you that schizophrenia does not exist, or that you should avoid the medical profession if you have it, are not acting in your best interest. On the other hand, "experts" who offer exciting treatments with exaggerated promises should be regarded with caution.

How is Schizophrenia Treated?

Although schizophrenia is not a "curable" disease in the usual sense, it is usually controllable. The proper treatment of schizophrenia includes the following:

- **Medication**
  Most patients with schizophrenia must regularly take maintenance medication to keep the illness under control. It is difficult for the doctor/psychiatrist to know which medication will work best for a given individual. Many changes in type of drug and dosage may be required. This period of trial and error can be

extremely trying for everyone involved. Some medications have unusual and difficult side effects, such as dry mouth, drowsiness, stiffness, nervousness, slowness, etc. Over time the body often adjusts to these effects.

- **Electroconvulsive Therapy (ECT)**
  ECT is the application of electrical current to the brain. It is mainly used for patients suffering from extreme depression who are suicidal and who for long periods seem unable to shake the depression under any circumstances.

- **Education**
  Patients and their families should learn all they can about all aspects of this illness by reading as much as possible. They should also be directly included in planning the treatment program. Families should know about the types of services that are available in their community including self-help groups, supervised housing, vocational opportunities and recreational programs. It is most important for the family to realize that the patient has a physical disease called schizophrenia.

- **Family Counselling**
  Family education and support groups are organized by Mental Health Clinic staff. They have proven to be extremely helpful to families. Since the patient and the family are under enormous emotional strain, it would be advantageous to consider regular counselling.

- **Hospitalization and Regular Follow-up**
  When very ill, the person with schizophrenia most often requires hospitalization. This will allow the patient to be observed, tested, diagnosed and started on medication under the supervision of trained staff. Hospitalization protects the patient from injury to self or others, and gives family members a needed break. Once the condition is stabilized and the patient is discharged from the hospital, regular follow-up should be provided by mental health professionals. Such follow-up will reduce the chances of the patient being readmitted to the hospital and provide the required support and empathy to the patient and the family. Permission of the patient is required for follow-up.

- **Rehabilitation Programs**
  Social skills training, along with residential, social and vocational opportunities tailored for persons with serious mental illness, have proved effective, even for the most disabled persons.

- **Self-Help Groups**
  Families can be very effective in supporting each other and in advocating for much needed research, public education, and community and hospital-based programs. Ex-patients can provide consultation, help and support for these efforts, as well as a network of support to individuals with schizophrenia.

- **Nutrition, Sleep and Exercise**
  Recovery from mental illnesses, as with any physical illness, is aided by well-balanced meals, adequate sleep and regular exercise. However, schizophrenic illnesses and the side effects of medication can complicate healthful eating, sleeping and exercising. There can be a loss of appetite, lack of motivation, and withdrawal from the normal cues for activity. The person may simply forget to eat, or become very suspicious about food. Isolation from other people and their daily routines can be a constant problem. Supervision of these basic functions may be required, especially if certain foods must be avoided for medical reasons. Be patient, and don't take their carelessness or disinterest personally.

Promising New Developments

We are on the verge of a knowledge explosion about brain chemistry. Many of the pieces of the puzzle are still missing for schizophrenia, but new technology holds great promise. Treatment, of course, will continue to be affected by these new discoveries.

Research indicates that schizophrenia is not "all in the mind". It is a physical disorder:

- **EEG's (electroencephalograms)** show that the electrical impulses used by the brain to send messages to other parts of the body are abnormal in many people with schizophrenia.
- **Chemical research** shows that there are definite chemical abnormalities of proteins and neurotransmitters in the brain. For example, some patients have been found to have an excess of dopamine (neurotransmitter) while others do not have sufficient amounts of this chemical.
- With devices such as **CT (computerized tomography)** and **MRI (magnetic resonance imaging – previously referred to as NMR, or nuclear magnetic resonance)** scans, scientists have been able to take pictures of the brain. These imaging tools show that the brain structure of some people with schizophrenia are different from people without the illness. About one-third of patients have enlarged ventricles (small spaces in the brain through which cerebral spinal fluid circulates). CT scans are fairly common in Alberta hospitals. MRI scans are available at the University of Alberta in Edmonton and the Foothills Hospital in Calgary.
- **PET (positron emission tomography)** scans show that the brains of people with the illness also function or work differently. Very often, there is decreased blood flow to the frontal lobes as well as decreased glucose utilization in the same area.

The CT and NMR (MRI) scans show the anatomy, the structure of the brain, but PET scans picture function. Active parts of the brain use more glucose, so PET scans taken after injections of glucose tagged with radioactive atoms can show which parts of the brain are being used during different activities. For example, when the person looks at a picture, the glucose instantly concentrates in the visual cortex at the back of the head.

"CT and NMR tell you whether the building structure is there, but PET tells you if there are any people in there, if they are having a party or what they are doing . . . It can truly give you the picture of a thought rather than the anatomy of the brain. It's perhaps five times more expensive than CT or NMR, but PET is a major tool," Dr. Seeman, a scientist at the University of Toronto, said.

Radioactive molecules have been designed which can be injected in solution into a patient's bloodstream. As the blood flows through the brain, the molecules latch onto the dopamine receptors, creating a map of their location and density.

PET scanners exist at medical research centres in Hamilton, Ont., Vancouver and Montreal and one is currently being built in Toronto.

PET shows picture of thoughts in brain

By Joan Hollobon
Globe and Mail, 1984

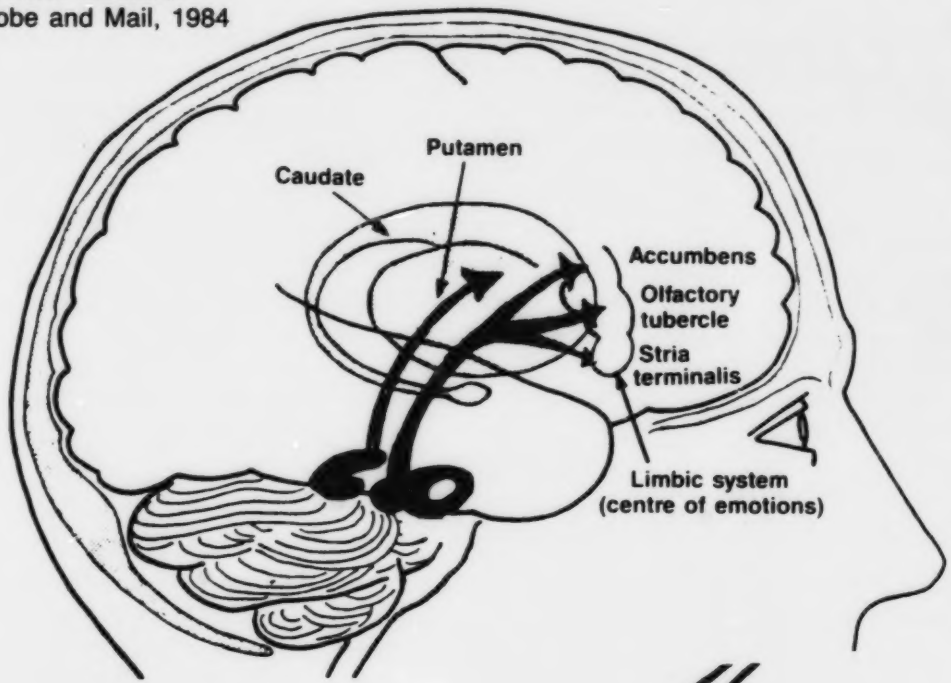
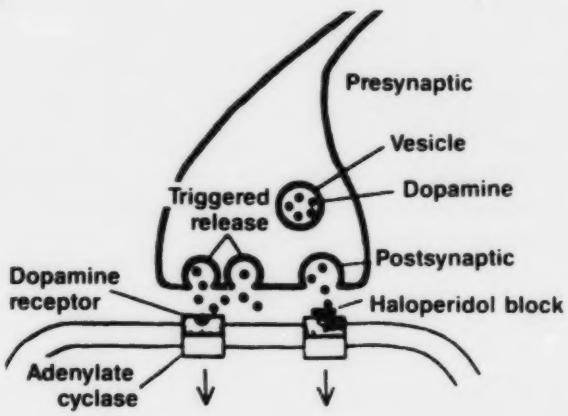


Diagram above shows three areas in the brain where an excess number of receptors have been found in schizophrenic patients. The three areas are the caudate, putamen and accumbens. At right, diagram shows how anti-schizophrenic drug, Haloperidol, blocks receptors.



Schizophrenia – brain disease or emotional disorder?

At last, it seems beyond dispute that the hallucinations, delusions, paranoid thinking and bizarre behavior typical of schizophrenia result from an organic abnormality in the brain first reported by a team of scientists at the University of Toronto led by Dr. Philip Seeman.

Dr. Seeman reported in 1977 that post mortem study of the brains of people who had suffered from schizophrenia showed an abnormally large number of dopamine receptors in three tiny central areas of the brain.

- Dr. Sandy McEwan, "nuclear medicine physician" at the Cross Cancer Institute in Edmonton, comments on an imaging device called a **SPECT (single photon emission computed tomography)** scanner which he refers to as the "poor man's PET". Using this scanner and a radio-active compound (HMPAO), it is possible to measure blood flow in the same manner as a PET scanner, but at significantly less cost. The results of SPECT studies show reduced blood flow in frontal lobes of patients with schizophrenia.

  Dr. McEwan foresees that this test may well become routine at some point in the future. Many large hospitals throughout the province already have the SPECT scanners.

Further new developments in research on schizophrenia are occurring in the field of genetics. In discussing one exciting new development, Dr. Barry Jones, a leading Canadian medical researcher in Ottawa, explains, "There are 23 pairs of chromosomes that exist in every cell in our body. They determine everything about us, our body build, hair colour, even how our brain functions. We inherit these 23 pairs from each of our parents.

"For the last 20 years we have known that schizophrenia runs through certain families. This indicates that there is a genetic component, i.e. a heriditary factor. Chromosomes carry the coded information for heredity in units called genes.

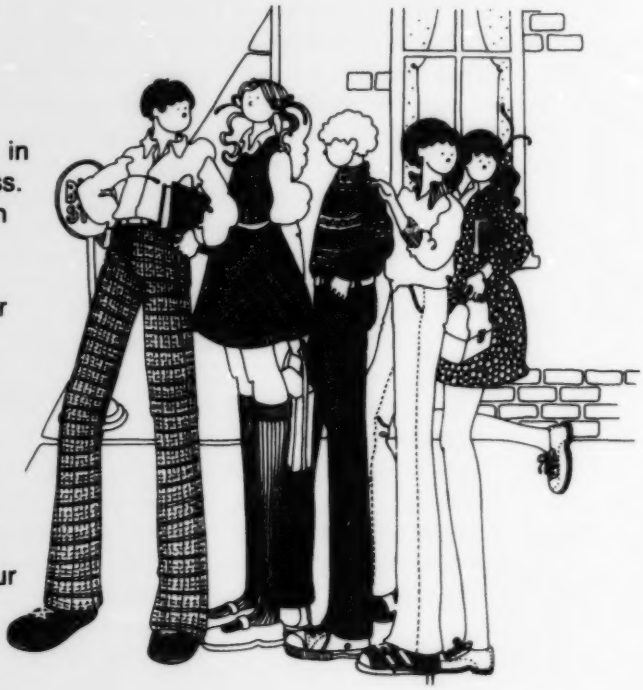
"It seems that one gene is 'coding' for the development of schizophrenia in some families. It can come from either side of the family. Research efforts have been looking for the location of this gene which could exist in any one of the 23 different chromosomes. It's as difficult as looking for a needle in 23 haystacks. Recent evidence has found this gene to be located on chromosome number 5."

Dr. Jones concludes by saying, "The implications of this are:

- schizophrenia is a genetic disease;
- in the future we may be able to diagnose people who are at risk for developing schizophrenia through genetic methods;
- by determining the function of the gene we may be able to discover new treatment for this disease."

Young People and Schizophrenia: Some Questions and Answers

"Schizophrenia affects many young people in the prime of their lives. It is a major set back in their plans and hopes for the future."
Dr. Ian Falloon



1. Q. **What are my chances of developing schizophrenia?**
   A. There is no way of knowing exactly who will develop the illness. However, about 1% or 1 in every 100 persons has the illness. Since schizophrenia tends to run in families, your chances of developing this disorder will be higher if someone in your family is schizophrenic. For example, it is estimated that:
   - if one of your parents or a brother or sister is ill, your chances are 10%
   - if both of your parents are ill, your chances are about 40%
   - if a nonidentical twin is ill, your chances are 10-15%
   - if an identical twin is ill, your chances are 35-50%
   - if you are a grandchild, niece, nephew, aunt or uncle of someone who is ill, your chances are about 3%.

   Schizophrenia does not discriminate between the sexes. Young men and women are equally at risk for developing the illness.

2. Q. **Can children develop schizophrenia?**
   A. Yes. In very rare instances, children older than five years of age have been known to develop the illness. They rarely display obvious signs or symptoms like hallucinations (false perceptions) or delusions (false beliefs) but are often described as being different from other children at an early age. Their illness is diagnosed when symptoms become more recognizable in adolescence or adulthood.

3. Q. **How can I find out if I am suffering from schizophrenia before it becomes serious?**
   A. You are advised to consult with a psychiatrist who has experience in treating schizophrenia.

4. Q. **Should I have children if I have schizophrenia?**

   A. Schizophrenia tends to run in families but that does not necessarily mean that you should not marry and have children. Since you will want to be a good parent and a good provider for your family, you will have to ask yourself some important questions:

   - Is my illness sufficiently under control that I can keep my job and help to raise my children?
   - Am I prepared to risk having a child who may develop schizophrenia? (The chance of each of your children developing schizophrenia is 1 in 10. If your spouse also has schizophrenia, the chance of each child developing the illness increases to 2 in 5.)
   - Will the stress and expense of raising children cause me to become ill again? Even more, what if one of my children develops schizophrenia?
   - Is my spouse a stable and capable person who can help to provide an orderly and peaceful home environment?
   - Am I a responsible person who will continue treatment in order to recover as fully as possible?

   As you can see, the decision will depend upon you and your situation.

5. Q. **How can I be considerate of a friend or classmate who has schizophrenia?**

   A. We all need good friends who are considerate of us through both good and difficult times. Young people with schizophrenia will value your friendship immensely. They may be excluded by others who are ignorant of the illness and who don't realize that many people with schizophrenia have high I.Q.'s and most look and act perfectly normal unless they are not feeling well.

   You can be a real friend by trying to understand the illness and educating others around you when the opportunity arises. Let them know the facts.

   As well, you can make a point of getting to know other members of your friend's family. They can help you learn about your friend so that you will be able to provide encouragement and develop a close and meaningful relationship. For example, they can tell you that your friend may become depressed and feel overwhelmed and discouraged because his/her life is seriously upset and the promise of a fulfilling future seems distant.

   Furthermore, when you and your friend are planning activities, you can show your consideration by remembering that:

   - He/She needs at least 7 hours of sleep each night. As well, your friend should go to bed at approximately the same time each day.
   - Responsibilities with deadlines such as term papers and studying for exams shouldn't be left to the last minute.
   - Drug use other than prescribed medicines can be very dangerous because they can cause a return of symptoms (relapses).

6. Q. **Can street drugs cause schizophrenia?**
   A. No clear evidence exists that street drugs actually cause schizophrenia. Since some persons who take street drugs may show schizophrenia-like symptoms, persons with schizophrenia have sometimes been accused of being "high on drugs". To help determine the actual cause of a person's behavior, blood or urine samples can be tested for street drugs at many hospitals or a physician's office.

7. Q. **Does a history of mental illness or schizophrenia in my family put me at greater risk to have a schizophrenic breakdown if I use street drugs?**
   A. A good deal of evidence exists to show that if someone has a genetic factor present, drugs such as cannabis (marijuana, hash, hash oil, etc.) can trigger an episode of schizophrenia, which may or may not clear up when use of the drug stops. If your family has a history of mental illness, extra caution might be wise.

   Street drug use can be dangerous for anyone, but for those diagnosed as having schizophrenia, it can be particularly hazardous. As mentioned in point #5, certain drugs can cause relapses and make the illness worse.

   Street drugs that should be avoided:

   - PCP
   - amphetamines
   - LSD
   - marijuana/other cannabis products
   - cocaine/crack

8. Q. **What about drugs such as alcohol and tobacco?**
   A. Moderate use of alcohol does not seem to trigger schizophrenia, but evidence shows that heavy use certainly does.

   Those on medication will want to be particularly careful. Since alcohol is a depressant, it can be life-threatening when combined with medicines like tranquilizers. The two multiply the effect of the other, sometimes with disastrous results.

   New evidence suggests the following can also trigger episodes of schizophrenia:

   - stimulants such as coffee and tobacco in large amounts
   - nasal decongestants

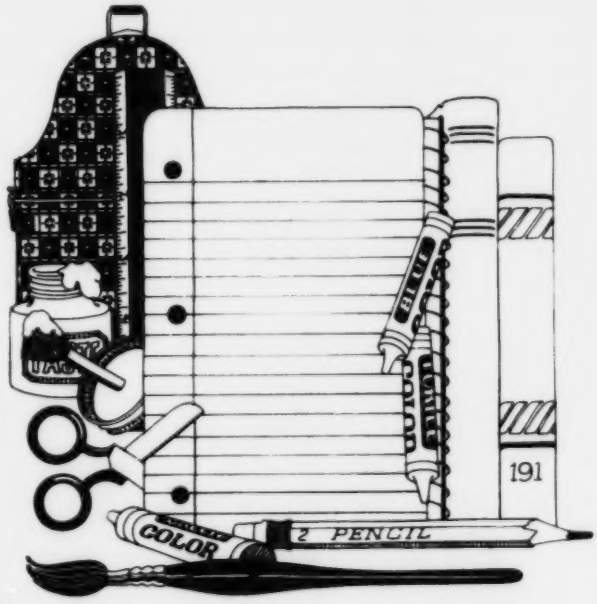
"Real friends will never pressure you to use drugs."

Schizophrenia and the Classroom: What Can Educators Do?

"Professionals ... must help the ill person set realistic goals. I would entreat them not to be devastated by our illnesses and transmit this hopeless attitude to us. I would urge them never to lose hope, for we will not strive if we believe the effort is futile."

Esso Leete (who has lived more than 20 years with schizophrenia and now commits herself to educating others about mental illness)

1. **Arm yourself with the facts.** Schizophrenia is a common illness which strikes many young people in their mid to late teens and early twenties. You will want to know that:
   - Most people with schizophrenia have normal intelligence and many have high I.Q.'s.
   - In very rare instances, children between the age of five and adolescence can develop schizophrenia. At this early age, frequently these children are described as being different from other children, as they are unlikely to display psychotic symptoms until adolescence or adulthood.



2. Wherever possible, **bring the illness into the open.** Openly discuss the issues with your students in classes such as Health and the Sciences. Such action can:
   - Help to dispel some of the myths and reduce the stigma associated with the illness.
   - Provide preventive information on precipitating factors such as drug abuse.
3. **Be alert to the early warning signs of schizophrenia.** Young people often have mood swings, become apathetic, and experience a drop in athletic or academic performance, amongst other things, but if such behavior persists, you may wish to consult with the student's family and assist the young person to receive an assessment.

4. **If you have a student in your classroom who has been diagnosed as having schizophrenia,** you can:
    - Reduce stress for the young person by going slowly during the confronting of new situations.
    - Help the young person to set realistic goals for academic achievement and for extracurricular activities.
    - Establish ongoing communication with the student's family for feedback on his or her progress. As a result, you may find that in order to optimize the learning situation, you will have to modify learning objectives, content of curricula, teaching methodology, student evaluation format, and other educational concerns.
    - Encourage other students to extend their friendship. Some may wish to act as peer supports when illness occurs and a catch-up situation is appropriate.

5. **If you have a peer counselling program in your school,** the illness of schizophrenia, as it affects young people and their families, could be one of the special needs areas addressed by the program.
    - Request professionals to provide some in-service training on the topic.
    - Run informational sessions on the illness for parent nights and student assemblies, and set up displays (ask a mental health organization to help you) for special occasions in the school library and counselling office.
    - Order print and audiovisual resource materials for your library. Just as you have reference and instructional materials available on other subjects, so you should have materials on schizophrenia.

Stigma and Mental Illness

"One thing I find really hard about my illness is the stigma."
Shawna, a person with schizophrenia.

What is the biggest problem people who have been treated for mental illness face when trying to resume a normal life? Most will say it is simply that others do not accept them. They have difficulty in finding friends, housing and work. They feel the sting of discrimination in almost everything they attempt. Many times they feel old friends and family are uncomfortable in their presence. They feel cut off from society.

They are victims of the stigma that still surrounds mental illness. Numerous scientific studies confirm what every mental patient feels — they don't belong, they are different, they are not valued. This stigma can become the most disabling feature of the illness.

Why Do Many People Find Mental Illness So Unacceptable?

- **Fear of Danger**
  One reason has to do with the common fear that mentally ill persons are dangerous, unpredictable and aggressive. The truth is, very few are dangerous. In reality, emotionally and mentally disturbed persons are usually anxious, fearful of others and passive. The myth of danger is perpetuated by the public's lack of knowledge and the media. Television and movie dramas frequently portray mentally ill persons as violent, homicidal objects of dread. Newspapers and magazines also exaggerate events where mental disorders are involved.

- **Fear of Criminal Intentions**
  Mentally ill persons are no more likely to commit crimes than the general population. However, the image of criminal intentions and behavior is wrongly emphasized when efforts to treat and safeguard the health of patients is misinterpreted. False impressions arise because:
  - mentally ill persons are sometimes treated in large institutions with locked doors, barred windows and out-of-the-way locations
  - restraints such as straight jackets, cuffs and padded rooms are sometimes used to control people
  - police become involved in difficult situations
  - the courts "commit" people for treatment when necessary
  - the media play up the myths.

- **Fear of Disease**
  After hundreds of years, "mental illness" was finally identified as a disease just like chicken pox, cancer or the common cold. Psychiatry was the last of the medical fields to develop. But this change from the realm of the witch doctor to the medical doctor has not erased the negative stigma, only lessened it somewhat. The public still has stong fears of hospitals, diseases, doctors, treatment — pain and suffering are all considered part of illness.

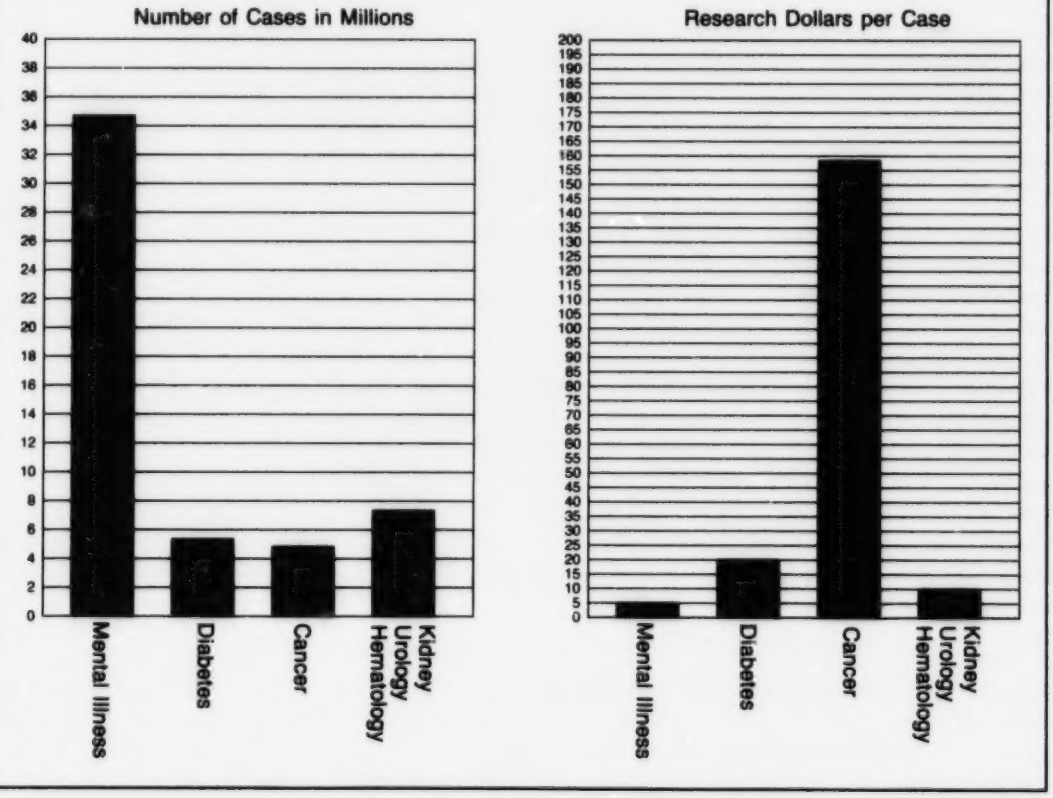
- **Fear of the Unknown**
  People often fear what they do not understand. And when they do not understand, they often make wild guesses. Some cultures believe mental illness is the work of evil spirits, while other cultures feel it is caused by bad blood, poisons, or a lack of moral integrity. As we learn more about the real causes of mental illness, many of these unhelpful beliefs will fade.

Better health education programs can help to correct these myths and misunderstandings. Providing psychiatric treatment in general hospitals rather than in mental hospitals and keeping recovering patients in their own communities with the necessary supports, will also help to overcome the prejudice against mentally ill persons.

How Has Stigma Affected Progress Into the Illness?

Stigma has caused families to shy away from public involvement for fear of creating further hurt or embarrassment for their ill person and other family members. As a result of these years of silence about the illness, the general public sees no evidence of an unmet need. With no advocates to present the facts about schizophrenia, funds necessary to carry research forward have fallen far behind those of other illnesses, as demonstrated by the graphs that follow. These statistics, although taken from U.S. sources, are comparable to the situation in Canada.

FY 1983 Federal Research Budget Comparison:
Selected Diseases By Prevalence vs. Dollars Per Case



Myths and Misconceptions About Violence and Schizophrenia

Schizophrenia is one of the most misunderstood diseases on the planet. Most people think that it means having a split personality. Most people are wrong. Schizophrenia is not a splitting of the personality into multiple parts, not a Jekyll/Hyde phenomenon, despite the popular hold of the Robert Louis Stevenson story. Most people with chronic schizophrenia are much too disordered to carry off double lives. Split personalities are rare and are a form of hysteria, not schizophrenia. Nevertheless, the idea that, "Schizophrenia equals split personality", is pervasive. When people in everyday life describe something as schizophrenic, they mean "split into two separate parts." How did the confusion start?

In 1911, the psychiatrist Eugen Bleuler invented the term schizophrenia to describe the disorder. (Schizophrenia comes from the Greek schizo meaning "split" and phrenia which means "mind".) What Bleuler was trying to convey by the term was the split between perception and reality. Today many psychiatrists regret the existence of the term because it is misunderstood.

But the split mind myth is not the worst to warp the perceptions of the public. That honor must be given to the myth of the violent madman. This misconception is so much a part of our culture that it is hard to recognize. It's like trying to see the air in front of our eyes. In films and print, people with schizophrenia are shown as menacing figures, ax murderers, chain saw specialists with rage in their eyes and blood on their hands. Because of these off-base depictions, millions of people have the erroneous idea that mentally ill persons must be violent.

For instance, no paper reports that a murder was committed by a raging sane man, even though in fact, the great majority of murders are committed by sane men. However, when a murder is committed by someone mentally ill, we read about it: "Ex-mental patient slays housewife" — never "sane man slays housewife." So ingrained is the myth of schizophrenic violence in our culture that most of us don't even recognize media prejudices against the mentally ill.

Here are the facts about violence and schizophrenia: mental patients are slightly less violent than nonmental patients. Psychiatrist Donald T. Lunde, in his book **Murder and Madness,** says the percentage of murders among people who have been mental patients is slightly lower than that in a general population. What seems to be true is that violent people will be violent whether they are sane or insane. The great murderers of history — those who plot mass political or religious exterminations — are lamentably sane. We may label them "insane" because we don't understand them, but it's doubtful that the people on trial at Nuremberg were anything but ordinary people committing extraordinary acts of violence. It's psychologically comforting to label all violent acts as "crazy" since it gets us "normals" off the hook. We think we couldn't do anything violent since we're "normal", but the fact is we could and do, every day. Ninety-five percent of the murders committed every year are committed by people who are sane.

Harvard psychiatrist Patrick O'Brien notes that many people with schizophrenia are exactly the opposite of the aggressive madmen of the myth — they are timid, afraid of being further hurt in their vulnerable state. O'Brien puts the matter succinctly: "If one is prone to violence to begin with, then a disorganizing process like schizophrenia, and especially like paranoid schizophrenia, may exacerbate those tendencies, but if

you are a calm, meek soul, such a process will result in a disorganized lamb and not a disorganized lion ... The important point to remember ... is that the violence and the schizophrenia are quite independent of each other."

It is a far different story if someone has a history of violence. Then it's necessary to take appropriate precautions. The point is, though, not to automatically be afraid in the presence of the mentally ill. It's not fair, and both suffer, the feared and the fearing.

(Excerpt from "Schizophrenia: Straight Talk for Families and Friends" by Maryellen Walsh.)

"A Sister's Need"

by Margaret Moorman

New York Times, September 11, 1988

My sister, Sally, is mentally ill. Now 47, she was first hospitalized almost 30 years ago, during her senior year in boarding school. Labeled schizophrenic then, she is now diagnosed as having bipolar — or manic-depressive - illness. Very generally speaking, schizophrenia causes thought disorders and bipolar illness causes mood disorders. When Sally has been manic, she has given away possessions, become obsessed with elaborate projects, stopped eating and finally, suffered from delusions.

Sally has not worked for pay since 1980, when she was forced to retire from the part-time position she held as a government clerk. For almost two years after losing her job, she lived in various apartments, halfway houses and rented rooms. In 1982, our mother brought her home.

I missed most of the crises of Sally's 20's and 30's. At first, being eight years younger, I was just not old enough to understand or even to pay much attention. As a teenager, I tried to ignore Sally because she was different, and I was afraid of being different myself. After our father died suddenly of a heart attack, our house became a place of quiet sadness. I spent little time there. I went away to college; after graduating, I moved to Seattle — about as far as one can get from Arlington. I kept in touch by phone, but I visited infrequently.

It isn't unusual for someone with a chronically mentally ill sibling to try to run away from family tensions. It was only by physically removing myself that I felt I could survive. I was abetted in my escape by my mother, who loved for me to be happy and was, I know, relieved to have one independent child. Unfortunately, like many excapees, I had mixed feelings about it, including guilt and dread.

I once thought that when my mother died I would rather kill myself than have to take care of Sally as she did. It seemed clear: either I would go back home to monitor Sally, or I would fail my sister utterly and be unable to live with myself. It was just a choice of which way to give up my life.

Resource Material On Schizophrenia

Available from:
Schizophrenia Society of Alberta
Provincial Office
Suite 102, 2405 - 9 Avenue S.E.
Calgary, Alberta T2G 4T4
Phone: (403) 262-4554

Pamphlets and Booklets

- *"Answers About Your Long-acting Medication"* by Sue Tourgis, et al. Squibb Canada Inc., 1989.
- *"Excerpts from Surviving Schizophrenia"* by E. Fuller Torrey, M.D., Squibb Canada Inc., 1985.
- *"Living With Schizophrenia"* by Daniel Y. Patterson, M.D., M.P.H., E.R. Squibb Canada Inc., 1982.
- *"Psychotherapy — A Guide to Psychotherapy"* by John F. Thornton and Douglas Frayn, Merrell Dow Pharmaceuticals (Canada) Inc., 1989.
- *"Resource Book For Families"*, Saskatchewan Friends of Schizophrenics, 1988.
- *"Schizophrenia: Courses and Outcome"* by John F. Thornton, Mary V. Seeman, Elizabeth Plummer, Merrell Dow Pharmaceuticals (Canada) Inc., 1989.
- *"Schizophrenia: Face It"*, Schizophrenia Society of Alberta (Alberta Friends of Schizophrenics) and Alberta Health, 1989.
- *"Schizophrenia: The Medications"*, by Mary V. Seeman, John F. Thornton, Elizabeth Plummer, Merrell Dow Pharmaceuticals (Canada) Inc., 1984.
- *"Schizophrenia: Questions and Answers"* by David Shore, M.D., Editor, National Institute of Mental Health. Rockville, Maryland, 1986.
- *"Schizophrenia: Rehabilitation"* by John F. Thornton, Mary V. Seeman, Elizabeth Plummer, Merrell Dow Pharmaceuticals (Canada) Inc., 1989.
- *"Schizophrenia: Returning Home"* by John F. Thornton, Mary V. Seeman, Elizabeth Plummer, Merrell Dow Pharmaceuticals (Canada) Inc., 1984.
- *"Schizophrenia: Symptoms and Management at Home"* by Mary V. Seeman, John F. Thornton, Elizabeth Plummer, Merrell Dow Pharmaceuticals (Canada) Inc., 1984.
- *"Schizophrenia: Youth's Greatest Disabler"*, Schizophrenia Society of Alberta and Alberta Health, 1990.

Articles

There are numerous published articles concerning schizophrenia. If you require specific information the provincial office or your local library may be of assistance.

Video Resources

- *"After The Tears: Teens Talk About Mental Illness In Their Families"* by United Mental Health Inc., 1988. (20 minutes)
- *"Biological Markers in Schizophrenia"* by Dr. Alan Boulton, University of Saskatchewan, 1987. (1 hour)
- *"Community Care Team: Five Part Course on Schizophrenia"* by Greater Vancouver Mental Health Services, Richmond, B.C. (5 one-hour tapes)
- *"Dr. Fuller Torrey: 1989 CFOS Annual General Meeting"*
- *"Living on the Edge"* by Rehabilitation Research and Training Center in Mental Illness, U.C.L.A. Training Centres. (30 minutes)
- *"Mental Illness: Awareness and Hope"* by American Mental Health Fund, 1988. (16 minutes)
- *"New View Society"* A look at the New View Clubhouse in Port Coquitlam, B.C., 1989. (17 minutes)
- *"Promise"* An award winning T.V. drama. (2 hours)
- *"Rehabilitating the Long-term Mental Patient"* by Robert Liberman and Associates, U.C.L.A. Training Centres. (30 minutes)
- *"Schizophrenia: The Seventh Wave"* by Greater Vancouver Friends of Schizophrenics, 1986. (28 minutes)
- *"Self Support Groups"* by Gerry Marshall, British Columbia Friends of Schizophrenics.
- *"Shattered Dreams"* CBC Man Alive documentary, 1989. (25 minutes)
- *"Strange Voices"*. An award-winning T.V. drama. (2 hours)
- *"Wills and Estates"* by Gerry Marshall, British Columbia Friends of Schizophrenics.

Books

- *"Welcome Silence: my triumph over schizophrenia"* by Carol North M.D., Simon & Schuster, 1987.
- *"Schizophrenia: Straight talk for families and friends"* by Maryellen Walsh, William Morrow publishers 1985.
- *"Children and Adolescents with Mental Illness: A Parents Guide"* edited by Evelyn McElroy, Ph.D. (The complete and compassionate guide, written by doctors, nurses, educators and parents.) Woodbine House, 1988.
- *"Families Helping Families: Living With Schizophrenia"*, collective, Avon Books, 1986. (For those who must cope with the daily reality of mental illness: the first complete guide. More than compassion, this gives practical advice from the families of the mentally ill.)
- *"The Caring Family: Living With Chronic Mental Illness"* by Kayla F. Bernheim, Richard R.J. Lewine, Caroline T. Beale, Contemporary Books, Inc. Chicago, 1982.
- *"Strategies: A Practical Guide for Dealing With Professionals and Human Service Systems"* by Craig V. Shields, Human Services Press, Richmond Hill, Ontario, 1987.

- *"Living and Working With Schizophrenia"*, Seeman, Littman, et al, University of Toronto Press, 1982.
- *"Living and Working With Schizophrenia"*, Second Edition, J.J. Jefferies, et al, University of Toronto Press, 1990.
- *"The Broken Brain: The Biological Revolution in Psychiatry"* by Nancy C. Andreasen, New York: Harper & Row, 1984.
- *"Louis Lambert"* a short story written in 1832 by Honore de Balzac included in collections of Balzac's works.
- *"The Shame of the States"* by Albert Deutsch, New York: Harcourt, Brace and Company, 1948.
- *"Crazy Quilt"* by Jocelyn Riley, New York: William Morrow, 1984. (The fictional account of a 13 year old girl whose mother has schizophrenia.)
- *"Is There No Place On Earth For Me?"* by S. Sheehan, Boston: Houghton Mifflin, 1982.
- *"Surviving Schizophrenia"* (a family manual) by E. Fuller Torrey, M.D., Harper & Row Publishers Inc., 1983.
- *"Schizophrenia and the Family"* by Anderson, Reiss, and Hogarty, The Guilford Press, 1986.
- *"The Voices of Robby Wilde"* by Elizabeth Kytle, Seven Locks Press, 1987.
- *"Homelessness: Critical Issues for Policy and Practice"* by the Boston Foundation, Boston: The Boston Foundation, 1987.
- *"The Homeless Mentally Ill"* by H. Richard Lamb, editor, Washington D.C., American Psychiatric Press, 1984.
- *"Nowhere To Go"* by E. Fuller Torrey, New York: Harper & Row, 1988.
- *"Coping With Mental Illness in The Family"* (a family guide) by Agnes G. Hatfield, Arlington VA, NAMI, no date.
- *"Hidden Victims"* by Julie Johnson, New York, Doubleday, 1988.
- *"Alternatives: A Family Guide to Legal and Financial Planning For The Disabled"*, Evanston IL, First Publications, 1982.
- *"Future Care Planning Guide"* by L. Mark Russell, Evanston IL, First Publications, 1989.
- *"Experiences of Patients and Families: First Person Accounts"*, NAMI Publication No. 2 (Second Series), Arlington VA, NAMI, 1989.
- *"In Search Of Housing: Creative Approaches to Financing Integrated Housing"* by Randolph, Frances, Bob Laux and Paul Carling, Burlington, VT, Univ. of VT, 1987.
- *"Care Of The Seriously Mentally Ill: A Rating of State Programs"* by E. Fuller Torrey, Sidney M. Wolfe, and Laurie Flynn, 2nd Edition, Washington, D.C., Public Citizen Research Group and NAMI, 1988.
- *"Creating A Caring Community: Developing Housing for Persons With Mental Illness"*, Third Printing, Arlington, VA, NAMI, 1987.

Community Services In Alberta For People With Schizophrenia

The **Mental Health Division of Alberta Health** is the main provider of community mental health services in the province of Alberta. Professional workers provide a variety of services in six mental health regions. For information and/or assistance, contact the regional office nearest to your home:

Edmonton Regional Office	427-4444
Calgary Regional Office	297-4520
Central Regional Office – Red Deer	340-5047
South Regional Office – Lethbridge	382-4468
Northeast Regional Office – Fort McMurray	743-7483
Northwest Regional Office – Grande Prairie	538-5160

How Are Mental Health Services Provided?

- Services are available free of charge upon your request, or through a referral by your family doctor, public health nurse, Alberta Family and Social Services, R.C.M.P., etc.
- Where the person affected refuses to see a physician and receive help and a family member or a friend feels that the problem is serious, information may be presented to a provincial court judge. Under the authority of the Mental Health Act, the judge can order a psychiatric examination. Then, if the doctor in charge feels that it is necessary, the person may be hospitalized long enough for assessment and treatment. (See also **Admission without patient consent** in **Glossary** at the end of this booklet.)
- All services are provided on a completely confidential basis.
- Services may be more effective if help is sought early. Many persons do not require hospitalization and can be helped while living at home.
- **For some services, there may be a waiting period.**

What Regional Services are Available?

- **Adult Services**
  Counselling or referral services are available for individuals, couples and families who are experiencing problems such as depression, alcohol and other drug abuse/dependencies, marital conflict, anxiety reactions, spousal abuse and poor self-esteem.

- **Child and Youth Services**
  Specialized services or referrals to specialized services are available for young people infant to 18 years of age and their families. Professional help is provided for poor school performance, behavioral problems, emotional troubles, delinquency, family conflicts, attempted suicide, drug abuse, parenting problems and stress reaction.

- **Consultation**
  Consultation services are available to other professionals such as family doctors, lawyers, clergy, teachers, and other community workers.

- **Educational Services on Schizophrenia**
  In order to inform the public about various aspects of mental illness, public education services are available to other agencies and community groups. Inquiries should be directed to the Regional Mental Health Clinic in your region, or the nearest chapter of the Schizophrenia Society of Alberta.

- **Inpatient Services**
  There are times when the severity of a mental illness requires a period of hospital care. Two provincial hospitals (Alberta Hospitals, Edmonton and Ponoka) as well as major hospitals in Edmonton and Calgary and each of the larger regional hospitals throughout Alberta offer assessment and treatment to those with mental illness.

- **Emergency Services**
  A 24-hour emergency service is available in each region through local hospitals. Regional Mental Health Clinics are generally open 8:30 a.m. to 4:30 p.m. Mondays through Fridays, except on holidays.

- **Residential Services**
  Approved homes, group homes and supervised apartments are available for individuals who are not able to live on their own or with their family. However, patients must meet entry requirements and comply with rules and regulations in order to be accepted.

- **Follow-up Services**
  The recovering patient may receive follow-up services from mental health professionals. Sometimes people who have schizophrenia will not agree to accept help. In these cases, the mental health worker must rely on family members for assistance. **Long-term care in supervised residences is in short supply. Crisis services are also not always available on demand. For this reason, family advocates must be prepared to bring their needs to the attention of the mental health professionals and the community at large.**

Research in Alberta

Research into schizophrenia and several other mental disorders has a long and proud tradition in Alberta. Research has been conducted at the Universities of Alberta (Edmonton), Calgary, and Lethbridge, as well as Alberta Hospital Edmonton, University of Alberta Hospital (Edmonton), Foothills Hospital (Calgary) and Calgary General Hospital.

To stimulate research in the province, the Government of Alberta has funded research into mental health issues through the Alberta Heritage Foundation for Medical Research and the Provincial Mental Health Advisory Council.

One million dollars has been raised in pledges through efforts by the Schizophrenia Society of Alberta, business, industry and concerned individuals to endow a chair for research on schizophrenia at the University of Calgary. The University of Calgary is seeking matching funds from Alberta Advanced Education through the Government of Alberta's Endowment and Incentive Fund. To date nearly $400,000 has been provided. This chair would be the first of its kind in Canada.

Research studies over the years include:

- 15-year follow-up studies of schizophrenic patients;
- studies which determine the prevalence of schizophrenia in the population (epidemiological research);
- studies of those individuals who suffer from other mental disorders in addition to schizophrenia (examination of co-morbidity and schizophrenia);
- studies of the functions of the nervous system, especially transmission of nerve impulses (neurophysiological), and studies of the nervous system's impact on behaviour (neuropsychological), as they pertain to schizophrenia;
- studies on the mechanisms of action of antipsychotic drugs (medications that work to control the symptoms of a psychotic illness);
- studies of the relationship between behavior and the chemical make-up of the nervous system (neurochemistry investigations);
- examination of sleep disorders in schizophrenic patients;
- classification of diseases (nosological studies) in schizophrenia.

Present research is trying to unravel the complicated genetic, biochemical and psychological basis for schizophrenia. Such data in the future will hopefully allow the ability to diagnose those at risk for schizophrenia at an earlier age, and thereby disrupt the accompanying progression of social pressures which can exacerbate the symptoms of the disorder. Perhaps in the future a cure will be found to help the many victims of this disease. Alberta has an active and leading role in these important studies.

Schizophrenia Society of Canada

#309, 95 Barber Greene Road
Don Mills, Ontario M3C 3E9
Phone (416) 445-8204
FAX (416) 445-2270

To understand why this organization was formed, some background information is required. The discovery of antipsychotic drugs resulted in dramatic improvement in many patients. Because of these encouraging results, it was thought that patients might better be treated in their home communities and large numbers of people were released from psychiatric hospitals (deinstitutionalized).

Unfortunately, the services necessary for adequate treatment and support of these patients in the community lagged far behind the need. Many families tried to make up for this deficit, but they were ill-prepared to cope with the demands of this complex disease. Hampered by lack of information and services, isolated by stigma, and frustrated by insensitive legal barriers to early treatment, they soon became exhausted and demoralized.

Inspired by the strong leadership of Dorothy and Bill Jefferies and Dr. Busse of Oakville, Ontario, a group of parents emerged determined to fight for a better life for their ill children. Their first efforts were directed to self-help through the exchange of practical advice and moral support. They called their organization, The Friends of Schizophrenics. In 1978, a national organization was formed, growing to include provincial branches in nine provinces and over 60 chapters. The Schizophrenia Society of Alberta is one of the provincial branches of this organization.

Schizophrenia Society of Alberta

Provincial Office
Suite 102, 2405 - 9 Avenue S.E.
Calgary, Alberta T2G 4T4
Phone (403) 262-4554

We can help. We are an organization of families and friends of those who have schizophrenia.

Work with us to promote and/or provide:

Education and **information** about schizophrenia.
Research into schizophrenia, its causes, treatment, cure and prevention.
Support for individuals and families affected by schizophrenia.
Funds necessary to accomplish these goals.

Addresses Of Provincial Offices

British Columbia Friends of Schizophrenics
6151 Westminster Highway
Suite 201
Richmond, British Columbia
V7C 4V4

941 Kings Road
Victoria, British Columbia
V8T 1W7

Manitoba Friends of Schizophrenics
4 - 1000 Notre Dame Avenue
Winnipeg, Manitoba
R3E 0N3

New Brunswick Friends of Schizophrenics
41 Morley Crescent
St. John, New Brunswick
E2J 2X5

Nova Scotia Friends of Schizophrenics
P. O. Box 178
Mount Uniacke, Nova Scotia
B0N 1Z0

Ontario Friends of Schizophrenics
P. O. Box 217, Station "O"
Toronto, Ontario
M4A 2W3

Prince Edward Island Friends of Schizophrenics
P. O. Box 785
170 Fitzroy Street
Charlottetown, Prince Edward Island
C1A 7L9

Quebec Friends of Schizophrenics
166 Chartwell Crescent
Beaconsfield, Quebec
H9W 1C3

Saskatchewan Friends of Schizophrenics
P. O. Box 305
Regina, Saskatchewan
S4P 3A1

Glossary: Understanding the Language of Schizophrenia

When trying to help a friend or relative who is experiencing an emotional or psychological crisis, you may encounter a number of terms and labels. This is especially true if you find yourself involved in the traditional medical system. Inside this system, standard diagnosis and treatments are often referred to with little explanation. A short glossary of the most commonly used terms follows:

- **Affective disorders**
  This psychosis is characterized by greatly exaggerated emotional reactions and mood swings from high elation to deep depression. A commonly used term is "manic-depression" although some people experience only the manic form and others only the depressed phase. These extreme mood changes are often unrelated to changes in the person's environment.

- **Admission with patient consent**
  The process of entering a hospital is called admission. Voluntary admission means that the patient requests treatment, and is free to leave the hospital whenever he or she wishes.

- **Admission without patient consent**
  A person may be admitted to a mental health facility and held there against his or her will. There are only two ways this can happen:
  - under admission or renewal certificates
  - under special court orders where a person has been charged or convicted with a criminal offence, they can be held at one of two Alberta forensic facilities.

  Before one can be admitted under certificates, two physicians, one of whom is a psychiatrist, must certify that the person is:
  - suffering from a mental disorder;
  - in a condition presenting, or likely to present, a danger to self or others;
  - unsuitable for admission to a hospital other than as a "formal" patient (see **Mental Health Act** in this **Glossary**).

- **Delusion**
  A fixed belief that has no basis in reality. Those suffering from this kind of disturbed thinking are often convinced they are famous people, are being persecuted or are capable of extraordinary accomplishments.

- **Diagnosis**
  Refers to the identification of a disease by studying its signs and symptoms. The medical diagnosis frequently is given in response to the question: "What is wrong?" Schizophrenia is one of many possible diagnostic categories used in psychiatry.

- **Electroconvulsive Therapy (ECT)**
  ECT is the application of electrical current to the brain. It is mainly used for patients suffering from extreme depression who are suicidal and who for long periods seem unable to shake the depression under any circumstances.

- **Hallucination**
  An abnormality in perception. Seeing, hearing, smelling, tasting or feeling things that are not there.

- **Medication**
  Pills or injections usually prescribed for psychiatric patients. Several types of drugs may be used, depending on the diagnosis. Ask your doctor or pharmacist to explain the function and names of all medications; to separate generic names from brand names in order to reduce confusion.

  1) Antipsychotics: Brand Names — Modecate, Largactil, Stelazine, Haldol, Fluanxol, Pipartil. Generic Names — Fluphenazine, Chlorpromazine, Trifluoperazine, Haloperidol, Flupenthixol, Pipotiazine. They help to calm agitation, diminish destructive behavior and hallucinations and may bring about some correction of disturbed thought processes. Side effects include changes in the central nervous system affecting speech and movement and reactions affecting the blood, skin, liver and eyes. Periodic checks of the blood and liver are advisable in any long-term use of such drugs.
  2) Antidepressants: Brand Names — Elavil, Tofranil, Ludiomil, Sinequan. Generic Names — Amitriptyline, Imipramine, Maprotiline, Doxepin HCL. These are normally slow-acting drugs but if no improvement is experienced after three weeks, they may not be effective at all. While they do have side effects, these are not as severe as those of the antipsychotic drugs.
  3) Mood Normalizers: e.g., Lithium Carbonate is used in manic and mani-depressive states to help stabilize the wide mood swings which are part of the condition. Regular blood level checks are necessary to ensure a proper medication level and there may be some side effects such as thirst and burning sensations.
  4) Tranquilizers: Brand Names — Valium, Librium, Xanax. Generic Names — Diazapam. These medications are used for calming agitation and anxiety.
  5) Side Effect Controls: Brand Names — Cogentin, Artane. Generic Names — Benztropine, Procylidine.

- **Mental Disorder/Illness**
  A substantial disorder of thought or mood which significantly impairs judgement, behavior, capacity to recognize reality or ability to cope with the ordinary demands of life; due to physiological changes caused by genetic, toxic, infectious, psychosocial or traumatic influences.

- **Mental Health**
  Describes the appropriately balanced relationship between individual functioning, their social group and the larger environment. These three components combine to promote psychological and social harmony, a personal sense of well-being, self-actualization and environmental mastery.

- **Mental Health Act**
  This act ensures the rights of patients who are being held under two certificates. These patients are then referred to as involuntary patients (or as formal or certified patients). The act provides for a **Mental Health Advocate** whose responsibility it is to investigate requests from involuntary patients to ensure their rights are protected.

- **Paranoia**
  A tendency toward unwarranted suspicions of people and situations. Those with paranoia may think that others are plotting against them or ridiculing them. It falls within the category of delusional thinking.

- **Psychosis**
  This term refers to any major mental disorder of organic or emotional origin, marked by disorganization and changes of personality and loss of contact with reality, often with delusions and hallucinations.

- **Schizophrenia**
  This is the most common psychosis or major mental illness. Common symptoms are personality changes, withdrawal, severe thought and speech disturbances, hallucinations, delusions and bizarre behavior.

- **Side Effects**
  A side effect occurs when there is an additional reaction that goes beyond or is unrelated to the desired therapeutic effect. Not all drug side effects are undesirable, but many are so unpleasant that in some instances the medication must be stopped. Less severe side effects include dry mouth, restlessness, stiffness, and constipation. More severe side effects include blurred vision, drooling, body tremors, nervousness, sleeplessness and tardive dyskinesia.

  Learning to recognize these side effects is extremely important because they are easily confused with the signs and symptoms of illness. For example, a lack of energy and general apathy can be a symptom of schizophrenia; drowsiness and a lack of energy can also be caused by antipsychotic medication. Certain other medications may be given to control these side effects. A doctor, pharmacist or mental health worker can explain the difference between symptoms of the illness and drug side effects.

- **Treatment**
  Refers to the giving of therapy or remedies designed to cure the disease or relieve its symptoms. Treatment in psychiatry is often a combination of medication (pills), counselling (advice giving) and recommended activities (programs) which together make up a treatment plan.